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ABSTRACT

The site visit report describes community living programs for persons with severe disabilities in the Wisconsin counties of Dane, LaCrosse, and Columbia. The visit attempted to identify and document promising practices through interviews with administrators, officials and staff; observations of three foster homes, two small group homes, and two supportive apartments; visits to two school programs; and a review of various state, county, and agency documents, plans, and evaluations. Promising practices are identified in the areas of county leadership (officials are committed to community integration); family support (Wisconsin has one of the most innovative family support programs in the country); and innovative community living arrangements including group home situations for only three or four individuals and individualized arrangements. The Community Integration Program provides innovative services for people coming out of institutions. (DB)

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COMMUNITY LIVING IN THREE WISCONSIN COUNTIES

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SITE VISIT REPORT

COMMUNITY LIVING IN THREE WISCONSIN COUNTIES

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INTRODUCTION

The State of Wisconsin has a history of innovation in community services for people with developmental disabilities. As long ago as the early 1970s, the state was recognized for its leadership in promoting alternatives to institutions. In a report issued in 1973, the President's Committee on Mental Retardation singled out Wisconsin's Department of Health and Social Services for its plans to develop community housing programs for people with mental retardation. Today, Wisconsin is home to some of the highest quality and most integrated services in the country. The state can proudly point to several innovative state programs, an effective protection and advocacy agency, a strong Developmental Disabilities Council and a number of creative and responsive community service agencies. In addition, the Madison Public Schools, in conjunction with the University of Wisconsin, has a national reputation as a leader in the integration of students with severe disabilities into regular schools (Taylor, 1982).

Despite the presence of excellent services throughout the state, Wisconsin continues to maintain a large number of people with developmental disabilities in institutions of various kinds. The state's three "DD centers," Central, Southern, and Northern, have a combined population of

approximately 2,000 people. According to a national study conducted by Braddock, et al. (1984), Wisconsin ranked in the bottom third among states in the depopulation of public institutions in the period from 1977 to 1984. Wisconsin also has several thousand people with developmental disabilities in county, nonprofit, and profit-making nursing homes and child-caring institutions.

In short, Wisconsin is a state that presents sharp contrasts in services for people with developmental disabilities. When viewed from one perspective, Wisconsin stands out for its innovation in advancing the state of the art in community services for people with developmental disabilities. When viewed from another, it lags behind an increasing number of states that have committed themselves to returning people with mental retardation and other disabilities to their rightful place in the community. This report looks at some of the good things in Wisconsin.

THE SITE VISIT

This report is based on a site visit to the State of Wisconsin in 1986.[1] The site visit focused on three counties: Dane, LaCrosse, and Columbia, and included: interviews with Dane, LaCrosse, and Columbia county developmental disability officials and staff; interviews with administrators of the Dane County Family Support Program, Lutheran Social Services, and Riverfront Activity

Center; observations of three foster homes, two small group homes, and two supportive apartments; visits to two school programs; and a review of a range of state, county, and agency documents, plans, and evaluations.[2] The purpose of the site visit was not to conduct an evaluation of state, county, or agency programs per se. Rather, the purpose was simply to identify and document promising practices and good ideas for serving people with severe disabilities in the community. Thus, the site visit was not directed at answering the question: "Are these state programs, counties, or agencies doing a good or bad job?" Instead, it was directed at the question: "What can other counties and communities within Wisconsin and other states learn from these programs in these three counties?" No claim is made that all services within these three counties are ideal or exemplary. In addition to this site visit, statistics and information gathered in late 1986 are incorporated into this report.

BACKGROUND

In Wisconsin, counties are responsible to "plan, fund, and administer" community services. The state operates the three public institutions ("State Centers for the Developmentally Disabled") and funds community services, but does not operate any community services itself. Quasi-independent community services boards, referred to as "51

boards," or "Human Service Boards" directly administer community services for people with developmental disabilities. There are 59 such boards statewide, with some being multi-county cooperatives. The state has established a range of funding mechanisms to support community services. The major funding source is "community aids," which matches roughly 90% state dollars to 10% county dollars up to a certain amount. In most counties, however, the county pays a greater proportion of funds for services. According to one county administrator, the average county match is close to 25%. In addition to this basic state aid, the state has a number of funding sources earmarked for specific purposes. For purposes of returning people from institutions or preventing institutionalization, three major state programs stand out (in addition, of course, to Supplemental Security Income or SSI). These include the Community Integration Program (CIP), the Community Options Program (COP), and Family Support. The Community Integration Program is a state "Medicaid waiver" program authorized by the federal Omnibus Reconciliation Act of 1981. In Wisconsin, the Medicaid waiver is used to support home and community-based services for people formerly residing in state institutions. Wisconsin is just now initiating CIP II which will be directed at people in nursing homes. The COP program provides funding for community services for people leaving nursing homes or at

risk of entering them. The Family Support program provides up to $3,000 per year per family to enable families to keep their children at home. This program is only available in selected counties. CIP and the Family Support program are described later in this report.

As might be expected, counties in Wisconsin vary widely in terms of the number and nature of community services provided to people with developmental disabilities. For example, the counties differ markedly in the proportion of people placed in state institutions, nursing homes, and private institutions as opposed to community settings and in the amount of funds available for community services. Some counties contract for most services, while others offer them directly.

Dane, LaCrosse, and Columbia counties are quite different from one another. Dane and LaCrosse counties encompass cities (Madison and LaCrosse) and have the advantages of having local branches of the University of Wisconsin within their boundaries. By contrast, Columbia is a rural county that does not have access to all of the resources of the other two. Brief profiles of the counties are as follows.

Dane. Dane county has the second largest number of people placed in foster family homes and small (three- or four-person) group homes in the state with 207 in 1985. In terms of small and large community settings up to ten persons, Dane county had 332 at the end of 1985. In 1985,

Dane county had 135 people living in state institutions and 196 people with developmental disabilities in nursing homes. Dane budgeted $1,454,434 in county funds for community services for the developmentally disabled in 1985.

LaCrosse. LaCrosse supported 64 people in foster family homes and small group homes in 1985. The county had 20 people in state institutions and 52 in nursing homes. The county budgeted $186,272 in county funds for 1985.

Columbia. A small county, Columbia had 35 people in foster family homes and small group homes in 1985, with 21 people in state institutions and 25 people with developmental disabilities in nursing homes. The county budgeted $31,949 in county funds for community services in 1985.

In comparison with other counties, Dane and LaCrosse do well consistently in terms of a low use of state institutions and nursing homes, while Columbia has a relatively high use of state institutions for its population and a low use of nursing homes.

Quite apart from placement and funding figures, Dane, LaCrosse, and Columbia are also marked by county leadership for innovative and integrated services in the community (although certainly other counties have demonstrated leadership and commitment).

PROMISING PRACTICES

County Leadership

A number of Wisconsin counties have demonstrated leadership in supporting integrated community services for people with severe disabilities.

A county-based system for providing community services like Wisconsin's has its distinct advantages and disadvantages. On the negative side, state and county relations may interfere with the pursuit of broader goals. As relatively independent units of government, counties may not share and may even resist state policies. In the case of deinstitutionalization, counties may not be willing to accept responsibility for serving people who previously had been served by the state and may view this policy as a guise for shifting the costs of services from the state to the county level. Further, the state may not provide the same level of funding for county-administered services as it does for state-administered services. Thus, one county official in Wisconsin stated that the legislature had just approved a major increase in funding for state institutions but had approved only minimal funding for county-administered community services.

On the positive side, counties tend to be more flexible and responsive than state service systems. Unencumbered by a massive state bureaucracy as exists in many states, counties have more room for innovation in exploring new and

better ways of serving people. In addition, under a county system, decision-making is more likely to be based on individual needs than on impersonal rules and regulations.

Wisconsin currently places responsibility for community services with the counties. While one might point out the advantages of a state or regional system of community services, the reality is that if people with developmental disabilities are to be served in the community, the counties must be centrally involved. In Wisconsin, the counties are the key.

Dane, LaCrosse, and Columbia counties seem to be trying to meet the challenge. To be sure, none of these counties is perfect. Each has a sizeable number of people remaining in institutions and nursing homes. Yet several things make these counties stand out from most service systems nationally, whether state, regional, or county.

1. Willingness to serve people with challenging needs. In Dane, LaCrosse, and Columbia counties, one can find a number of people with severe and multiple disabilities, including medical involvements and challenging behaviors in the community. In most communities, some of the people served in these counties would not be considered for community placement. Each of these counties has also accepted people returning from the state institutions who present special challenges and is planning to serve more. As discussed later in this report, county officials and staff

see certain advantages in participating in the CIP program. Yet the underlying reason that they are serving these people is that they believe they belong in their counties. As one Dane county administrator explained, "Those people are ours. They are from Dane county." A Columbia county administrator expressed the same sentiment: "Here in Columbia county, we believe in taking care of our own." This stands in stark contrast to many communities across the country where institutional residents are viewed as the "state's people" who do not have the right to return home.

2. Commitment to community integration. In each of these counties, officials are not only willing to serve people with developmental disabilities in the community, but are coming up with innovative ways to integrate people fully into community life. All three counties are moving toward more flexible and integrated residential and vocational services; specifically, away from group homes to families for children and supportive individualized living arrangements for adults and away from sheltered workshops and segregated day activity centers to "supported work" and community vocational services. A Dane county administrator commented, "Small living arrangements are important. We don't want large facilities." The director of services in Columbia county had this to say about segregated vocational services: "I don't like sheltered workshops. They're like institutions. They keep high functioning people to keep up

their production levels." As an indicator of its commitment to develop innovative integrated services, Dane county has initiated and cooperated with numerous external reviews of its case management, foster care, and residential services.

3. Administrative leadership. Good services seldom emerge on their own. For good ideas to become a reality, it takes administrative leadership and commitment. When visiting these counties, one gets the sense that administrators do not simply let good things happen, but take an active role in making them happen. In Dane county, administrators have strongly supported and found the dollars to fund innovative agencies like Community Work Services and Options in Community Living. In Columbia county, the director of services for the developmentally disabled has actively pursued a range of state funding sources and has helped create new agencies when necessary. The LaCrosse county director recently left his position for one in Minnesota. By all accounts, he was a strong leader and shrewd administrator who had a strong vision of what services should look like and was willing to take the steps necessary to make that vision come to life. A vocational agency administrator in LaCrosse county recalled how his agency developed a supported employment program: "About four years ago, (the former county director) called me on the phone and said, 'We want to move in the direction of supported employment. If you want to start a program,

fine. If you don't, I'm taking $30,000 from your budget and finding someone who will.' So we decided to start the program." According to various sources, administrators in all three counties have also been willing to finagle budgets and mix funding sources to support innovative services.

Setting Priorities for Case Management Services

Dane County has implemented a sound and equitable approach for assigning case managers to individuals with developmental disabilities.

Like LaCrosse and Columbia counties, Dane county contracts for all service for people with developmental disabilities except for case management. The county provides case management itself (although one agency, Options, has its own case managers). According to Dane county adminisators, the separation of case management from other direct services is an important safeguard. When case managers do not report to providers of other direct services, they are more likely to act as advocates for individual clients. As one administrator explained, "Our case managers are our most valuable source of information about what is happening to clients. You have to have people you can trust."

Dane county's case management system has received two major external reviews, one conducted by the Wisconsin Association for Retarded Citizens in 1982 and one by the Wisconsin Coalition for Advocacy in 1984. After the 1982 review, the county made a number of changes in its case

management system. The 1984 review was extremely positive about Dane County case managers, but pointed to some broader service system issues that impacted on their role.

Based on a cursory review of Dane County's case management system during the site visit, it seems clear that other counties and service systems can learn a number of things from how things are done there. What stands out especially as a "promising practice" is Dane county's scheme for setting priorities for case management services.

This is a world, and an era, of finite resources for human services. There are never enough funds available to pay for all of the services needed by all of the people. The challenge is to find the most equitable and effective way of setting priorities for services.

Like other service systems, Dane county has many people in need of a range of services and limited funds to pay for them. While it funds services to over 1,000 people with developmental disabilities, it maintains a waiting list of 240 for residential services and 150 for vocational services (the county consciously maintains a waiting list to substantiate the demand for services).

Dane county employs six full-time and one half-time case managers. How should these case managers be assigned to people? One way would be to assign a case manager to everyone who receives services or who is on a waiting list. This is what many service systems do. The problem with this

is that case managers try to do everything for everyone and end up doing nothing for anyone. Another way is to assign case managers on a "first-come, first-served" basis. This does not take into account people's needs.

Dane county has come up with another way of dealing with the problem. As a means of insuring that case managers have the ability to provide responsive and effective services, the county places a maximum of 25 on each case manager's load. In order to make sure that people who are most vulnerable receive case management, it has developed a set of criteria for determining who is a high priority. These criteria include:

1. Person at risk of institutionalization.
2. Person who does not have another involved person in his/her life.
3. Person who has problems speaking for him/herself.
4. Person experiencing a transitional age point.
5. Person needing/receiving services across several funding/disability systems.
6. Person receiving services from more than two agencies within the USB-DD (Unified Service Board-Developmental Disability) system.

In addition to these criteria, the county looks to other factors such as length of time on the waiting list in assigning case managers. According to the case management supervisor, they also attempt to have a case manager

assigned to at least one person within every living arrangement within the county. This means that even though they may not be able to provide case management to every person, they have first-hand experience with a larger number of people's living situations. Apart from the normal case management assignment procedure, the county must also provide case management for people funded through the Community Integration Program, the costs of which are reimbursed through this program.

Dane county's scheme for setting priorities for case management is not the only way to deal with the problem of finite resources. However, it does represent a fair way of making hard choices.

By several accounts, the county's case managers do a good job of serving the people they are assigned. According to the evaluation by the Wisconsin Coalition for Advocacy, "Case management staff show strong commitment to their clients, a high level of competence, and remarkable awareness of what they are doing, the reasons behind it, and the problems they are facing. Small caseloads and emphasis on intensive, personal, long-term involvement with clients have resulted in a generally high level of satisfaction with the services, expressed by clients, family members, service providers, and other USB staff." A foster family in Dane County had this to say about their case manager: "She's outstanding. . . .She's always there. . . .She says, 'Call

me anytime, day or night.'" From a family's perspective, that's one of the most important things to have in a case manager.

Family Support

Wisconsin has one of the most innovative family support programs in the country.

A number of years ago, Ed Skarnulis, then of the Eastern Nebraska Community Office of Retardation (ENCOR) and now head of Minnesota's department of mental retardation and developmental disabilities, offered the following advice to service systems: "Support, don't supplant the family." Too often, state and other service systems have made it easier for families of children with disabilities to seek out-of-home placement than to keep their children at home. From either an economic or humanitarian perspective, this does not make sense. Resources should be devoted to supporting families to care for their children.

While many states have begun to establish respite and other programs for families Wisconsin's Family Support Program stands out for its responsiveness to the needs of individual families. Unlike many other schemes, the program is flexible, individualized, and "family-centered."

Like other community services, Wisconsin's Family Support Program is administered by counties. Counties may either provide services directly or contract with local agencies. The Family Support Program provides up to $3,000

in services for families of children with severe disabilities. The state is authorized to approve additional funds to families upon the request of the local administering agency. Under state legislation, 10% of the funds allocated to a county may be used to pay for staff and other administrative costs; the rest must be spent directly for family support services.

The Family Support Program can be used to pay for a broad range of services families may need. As Linda Brown, one of the parents participating in the program in Dane county, has stated, families of children with severe disabilities can have a variety of extraordinary expenses: "Along with the stress that arises from living much of the time on the edge of life, we families deal with things most families never have to consider: occupational, physical and speech therapy; special feeding techniques, utensils and foods, special equipment like wheelchairs, bolsters, wedges, seats, splints, braces, and hearing aids; life support equipment like oxygen, apnea monitors, ventilators, nebulizers and compressors, various tubing, trachs, trach masks, and suctioning equipment. There are even special dressings for all of the tubes inserted and sterile water for all the special techniques. On top of these are countless medications, diapers, usually far past the normal toilet training stage and often special clothing."

The Family Support Program lists 15 specific categories

of services a family can receive:

1. Architectural modifications to the home.
2. Child care.
3. Counseling and therapeutic resources.
4. Dental and medical care not otherwise covered.
5. Specialized diagnosis and evaluation.
6. Specialized nutrition and clothing.
7. Specialized equipment and supplies.
8. Homemaker services.
9. In-home nursing and attendant care.
10. Home training and parent courses.
11. Recreation and alternative activities.
12. Respite care.
13. Transportation.
14. Specialized utility costs.
15. Vehicle modification.

In addition, the program can pay for the costs of other goods or services as approved by the state.

As the first step in participating in the program, families receive a needs assessment and family plan. To be eligible, families must have a child with a severe disability according to state criteria, which parallel the federal definition of developmental disabilities. While there is no income test for the program, families may be expected to share some of the costs of services. Under state legislation, a child is defined as a person under the

age of 24. In practice, however, the program is directed at families of children in school. The state must approve services for families of children ages 21 through 23.

According to documents describing the Family Support Program, the needs assessment looks at the family's existing formal and informal support networks. The family plan attempts to build on these. For example, a state document indicates that a neighbor may be looked to to provide transportation for a child. The plan specifies what services a family will receive through the program. These services may be paid for directly by the agency or the family can be given a grant to pay for them (families must keep receipts).

In addition to providing support services, the Family Support Program is intended to help coordinate other services a family receives: "An important role for the family support coordinator or case manager is to act as a kind of service broker assisting the family through the bureaucratic maze of available programs and services. The worker can also act as an advocate in helping the family to make maximum use of community services, such as community recreation programs, medical and dental services, public transportation, and other generic service providers."

In Dane county, family support services are provided by the Family Support and Resource Center, a private agency with a board composed of 50% consumers. The center has a range of funding sources and administers the state's Family

Support Program.

Located in a typical looking storefront, the Family Support and Resource Center employs seven staff; one-and-one-half family coordinators, two respite workers, a part-time director, a bookkeeper, and a secretary.

The center provides three types of services to families. The first is information and referral. As the director explained, "We're a central place. We offer parents a place to start and serve as a clearinghouse." The center maintains listings of services in Dane county.

The second type of service is the family support program, which pays for services families need. This is funded both through state Family Support Program funds, as described above, and state COP (Community Options Program for people "at risk" of institutionalization) funds. The center supports 50 families through the Family Support Program, with 15 to be added this year, and 20 natural and foster families through COP. Under the COP program, families can receive up to $550 worth of services.

According to the director, the center can pay for "anything that will help the family take care of the child." She described one rural family with a teenage son with spina bifida who requires an enema every other day. She characterized this as a "stress point" for the family. The program pays for a neighbor to provide the enemas at $5 to $6 per hour. She also mentioned a family with a teenager

with autism who received an alarm that alerted the parents when the child tried to run away.

The director compared Wisconsin's Family Support Program with Michigan's, which entails a cash subsidy paid directly to families. She commented that Wisconsin's approach has more "accountability" and insures that funds are spent on expenses directly related to the child with the disability. She also stated that Wisconsin's approach puts families in touch with people who can help them: "Although some families don't want this, we can offer case coordination and an ally."

The final type of support offered through the center is respite. This is provided above and beyond other family supports. Although 250 families are registered to receive respite, only 190 families used it in the past year (88% were families of children). Families can receive 14 days or 140 hours of respite care per year. However, the respite program is very flexible: "We have flexibility. We can allow more days if a family needs it."

The center offers both in-home respite (primarily home aides, but the program can pay for nurses) and out-of-home respite in foster homes. It also has foster care providers on call for emergencies. The center's respite workers recruit and train all respite providers.

Many counties in Wisconsin offer some kind of respite or family support services. However, only 17 community

boards (23 counties) receive funds through the Family Support Program. Seven additional counties have been awarded grants, although funding is not now available for these. There is a budget proposal for the '87-'89 biennial period requesting funds to allow services to continue for children and their families currently participating in the program.

It seems a shame that the Family Support Program is not available to families throughout the State of Wisconsin.

Innovative Community Living Arrangements

With the support of state programs like the Community Integration Program or CIP, some counties and agencies in Wisconsin are developing some of the most innovative and responsive community services in the country.

The state of the art in community living is evolving in an incredibly rapid pace across the country (Taylor, et al., 1986). Many programs in Wisconsin stand at the forefront. Throughout Wisconsin, people are coming up with innovative ways to integrate people with severe disabilities into the community.

Many counties and agencies in Wisconsin are moving in an exciting direction.

Toward families for children. In Michigan, Nebraska, and parts of Kentucky, agencies are finding foster families for children with the most severe disabilities. The Macomb-Oakland Regional Center in Michigan no longer places

children in group homes, let alone state institutions or nursing homes. At Macomb-Oakland, people have found ways to recruit caring and committed adoptive and foster families for all the children with medical involvements, challenging behavior, and multiple disabilities who need them. The same thing is starting to happen in Wisconsin. This is true despite the fact that, in contrast to Michigan and other states, foster homes in Wisconsin are recruited and licensed by generic social services agencies, which do not have a strong track record serving children with challenging needs.

DAVID* IN DANE COUNTY

David is a four-year-old with a lot of problems. As an infant, he suffered intracranial bleeding and seizures. He is blind, has a curved spine, is significantly delayed in his development, and has a range of mobility problems.

After a period of hospitalization, David wound up at one of the state's institutions. For some complicated reasons, David could not return home. While at the institution, he was visited regularly by Ron* and Dorothy,* a middle-class and middle-aged couple who happened to be his great-uncle and great-aunt. With

*pseudonym.

funding from the CIP program, Ron and Dorothy decided to become David's foster parents. As Ron later explained, "Well, we lost a child a number of years ago and we just couldn't stand to see David there. He's family."

David goes to school half-days four days a week. He also receives physical therapy and occupational therapy. Two weekends a month, he goes to his natural parents. According to Ron and Dorothy, they take David to restaurants and church with them.

Ron and Dorothy speak glowingly of David's pediatrician and case manager. They say that the case manager is outstanding and is there when they need her.

During the half-hour visit, Ron and Dorothy held, hugged, played with, and cooed at David. First Dorothy held him and then Ron. Bouncing him on her knee, Dorothy beamed as David giggled. Hugging him, she whispered, "Give auntie love." Ron leaned over, took David, bounced him on his knee, kissed him, and cooed, "Love." Pointing to Dorothy, he said, "See, ma-ma, auntie ma-ma." Dorothy said, "The more love you show, the more he'll do for you."

LINDA* IN LACROSSE COUNTY

Linda is a dark-haired, six-year-old girl. When she was six-months-old, she was involved in a serious accident. She is severely disabled. According to Linda's teacher, she has a shunt, is susceptible to

upper respiratory infections, and requires total care. The teacher has serious doubts whether Linda has any purposeful movement. Most of her educational program consists of physical therapy and feeding.

Today, Linda lives with Gertrude* and William,* an older couple, in a rural area of LaCrosse county. Placed there from a state institution through the CIP program, she has lived there almost two years.

As a foster family, Gertrude and William receive $950 per month. They also receive respite two weekends a month and a nurse visits the home. A physical therapist taught Gertrude leg exercises, arm exercises, positioning, and postural drainage.

When asked to describe what Linda is like, Gertrude says, "She's pleasant, nice. She's good company. . . . She hears very well." Linda goes to school half-days now and is scheduled to go full-days next year. Gertrude does not seemed pleased by this: "I don't want her going a full-day. I like mornings with her. I don't know what I'd do without her." Gertrude explained what changes she has seen in Linda since she has lived there: "She laughs. She didn't do that before. . . . She's doing pretty good." When asked what Linda needs, she answers, "A lot of loving."

Gertrude describes Linda as a regular part of the family: She eats everything we do. . . . If she doesn't like it, she spits it out. She doesn't like chicken....

We take her to church, the grocery store, and everywhere we go."

Asked if it was difficult taking care of Linda, Gertrude said it was no trouble at all: "You don't have to chase her around the house."

A mother of 13 children who have left home and numerous grandchildren and great-grandchildren, Gertrude used to work at a children's institution and provided respite care after that. When she learned about Linda, she visited her at the state institution and decided immediately to take her in: "She was on a mat with a lot of other kids." Gertrude would like to have another foster child.

Gertrude is proud to show visitors Linda's room. It is filled with dozens of stuffed animals and mobiles.

Gertrude does a lot for Linda, and Linda does a lot for her.

KENNY* AND KAREN* IN COLUMBIA COUNTY

Kenny and Karen live with the Ward* family in a farmhouse in rural Columbia county. They have lived in the house for about two-and-a-half years. The Ward's have been their foster parents for almost a year. Their former foster family had to move out of state. When they did, their in-laws decided to move into the house and become Kenny's and Karen's foster parents.

Kenny is ten-years-old and has a multitude of problems. He might be labeled severely retarded, autistic, and multiply disabled. He has mobility problems and uses braces and a walker: "He used to be in a wheelchair when he was at the institution, but he doesn't need that now." He also abuses himself, hitting himself in the face, and lost sight in one eye while living at the institution as a result: "He's been hitting himself a lot less, though. He's been ill this week and he hits himself more then he's not feeling well. He can't tell you in any other way that he's ill."

Karen is almost 18. Although she has hydrocephaly and a large and misshapen head, she can walk with some difficulty and seems very alert: "Some people still stare and some kids make fun of Karen. My other kids are getting used to it. People at the store are used to them and are very kind. My other kids stand up for Karen, like on the school bus."

Kenny's and Karen's foster mother, Helen,* is a woman in her 30s. In addition to Kenny and Karen, Helen and her husband have two "typical" teenage foster children and a 15-year-old son of their own. According to Helen, "Kenny loves my natural son. . . . He gives Kenny a lot of attention. He plays with him and roughhouses with him on the floor, and Kenny loves it. My natural son really loves Kenny. . . . He's the little brother he

never had."

Helen described Kenny: "Kenny has to be dressed and put into his braces. He has to have his diaper changed 24 hours a day. He eats by himself now. He's learned a lot. . . . He's made progress on his walking. Now he's gotten to take a couple of steps. . . . Kenny understands a lot more than people give him credit for. He understands, 'No.' He has a good personality. He's cute. He giggles. He's a kid."

Then she described Karen: "When Karen first came, she just sat there. She's changed a lot. She has a personality of her own. She's a stinker. The other day I was standing on a stool and she came up behind me and pinched me. She loves men. Karen is learning to do things by herself. She always wants to be helpful. . . Karen drools and wears wrist bands to wipe it off. I shower her every day in the morning. . . . After I shower her, I blow dry her hair so she can go and catch the bus. She can dress herself. All I have to do is lay her clothes out."

Helen gives Karen prompts to do things like hanging up her clothes and going to the bathroom. Noticing that Karen's hair was mussed after taking off her hat when coming home from school, Helen took a brush and said to Karen, "Can Mom comb your hair?" After brushing it, she said, "There you go, sweetie."

As a foster family, the Ward's receive $1,000 per month for both Karen and Kenny through CIP. They also get 10 hours a week of respite for both children. Karen also goes out on Saturdays with a worker from Lutheran Social Services.

Helen recalled what she thought about becoming a foster parent for Karen and Kenny when the in-laws said they were moving out of state: "I jumped at the chance. . . . At first I was scared, though. I didn't know what to expect. Now I've learned that it's no problem."

Helen talked at length about being a foster parent: "It's not boring. There's a lot of rewards. I wanted more kids. Now I have Kenny and Karen. I wouldn't have thought that I'd like it so much. . . . For other families, what it would take is to get to know the kids. Take them in and get to know them. . . . Kids like Kenny and Karen used to be shut up and forgot about. I think it's important for other people to see them and get to know them. If you can turn one person around, you've accomplished a lot.

"Well, I used to be bored. Now I have a lot to do, and I like it. They leave here for school at 7:10 or 7:15 and come home around 3:10 or 3:20. I have a lot to do while they're gone, though. I have a <u>lot</u> of meetings."

When asked how long Kenny and Karen will live with

the family, Helen said, "They can stay here as long as they want. Kenny and Karen aren't going to be leaving for a while."

Toward smaller group homes. In Dane, LaCrosse, and Columbia counties and among many state staff, there seems to be a consensus that large group homes are not the "answer." While group homes with six, eight, or more people may represent an improvement over institutions, they too often take on some institutional features. It is difficult, if not impossible, to treat people as individuals in a large group setting, especially when it comes to serving people with severe disabilities and challenging needs. In these counties, people are turning to smaller group homes and other, more individualized alternatives for people with developmental disabilities. Dane county administrators do not want to develop any more group homes. In fact, according to one administrator, "We have big fights over whether residences should be two versus four." Similarly, LaCrosse county is looking to group homes and other living arrangements for no more than three or four people as placements for people. Columbia county does not want to develop any group homes. As the director explained, "I don't want to see any group homes. The way group homes operate is that you identify the needs of the people through the needs of the program."

The most exciting and innovative services being developed in Wisconsin are the individualized and "person-centered" options described in the next section of this report. From the vantage point of many states that are developing group homes for six to twenty people, or even more, three- to four-person group homes seem like an attractive alternative.

A NICE APARTMENT

Cindy* is a woman in her 30s who has Prader-Willi's Syndrome. Through the CIP program, she moved from a state institution to an agency-operated group home where she lives with two other "residents" and a live-in staff member.

The "group home" is actually an apartment located in a relatively new apartment complex in Madison. The apartment looks nicely furnished and has several bedrooms, a small living room, bathroom, dining area, and kitchen. The staff member has a puppy.

The staff member lives and works at the apartment five days a week and then has two days off. She has been working there since October and previously worked in a large group home in another county. She explained that she likes the smaller setting a lot better: "We can go out a lot easier than you can in a large group home. With only three people, they don't stand out as

much and blend in better." She said that they go out to restaurants and to a weekly dance at the civic center. The women also go swimming on Tuesdays. She also said that she is trying to teach the women to go out independently on their own. Cindy has a part-time job at a nursery in Madison.

According to the staff member, Cindy can do many things for herself. She said that she can cook her own breakfast, although she "needs assistance" cutting. During the visit, in preparation for dinner, the staff member took out a can and asked Cindy to open it with a can opener. Cindy worked slowly but stayed with it.

A BEAUTIFUL HOUSE

Mary* is 32 and has severe physical disabilities. She uses an electric wheelchair and, although she cannot speak, has a communication board. Funded by the CIP program, she lives in an agency-operated small group home, with two other people, with a fourth scheduled to move in, and with a live-in staff person.

Mary's group home is pleasant, attractive, and luxuriously furnished. Through a loan from the Wisconsin Economic and Housing Authority, the house was renovated to make it fully accessible to people in wheelchairs. The kitchen area, including the sink and range, was arranged so that people in wheelchairs could use all of the facilities, and adaptive switches were on many of

the kitchen devices. Each of the bedrooms in the group home was filled with people's individual possessions. A small dog was in the home.

According to group home staff, Mary has made a lot of progress since she's lived here: "If you don't know her, it might not seem like a lot of progress, but it is. People might think it's minor, but with Mary progress is slow." The staff members went on to explain that Mary has come along in her toileting, learning signs on her communication board, using a swivel spoon to eat, and putting things into and taking them out of the washer and dryer.

The agency director explained that this house used to serve as a "transitional" group home for people with mild disabilities, but that it now served people with more severe disabilities. She said that this home cost $76 per person per day, which was more than an eight-person group home the agency operates, although this home also has people with more severe disabilities.

When asked about the advantages of a smaller group home, one of the staff members answered, "When you have eight residents and all the staff, you have too many people in one place. It's not a home anymore."

The agency director and staff spoke at length about the neighbors. The director explained, "We've never had any problems. The only time we ever had any complaints

was from an elderly woman across the street soon after we moved in. She called the police and accused us of running a brothel. One afternoon, she saw three separate men come and go. One was a psychologist, one was. . . . She thought this was a brothel."

A former live-in staff person at the house continued: "The neighbors have been fine. We didn't think the neighbors wanted anything to do with us. Then one Christmas a little old lady down the street brought a cake over for us. Last fall, another neighbor showed up with cookies. Another neighbor brought us vegetables from his garden.

"We always make sure that there are flowers out in front, and the outside of the house really looks nice. When I was here, I went out of my way to get along with the neighbors next door. I volunteered to help him prune his trees and then he helped me with mine. Part of the job is to get along with the neighbors."

The agency director commented, "We have a snow blower at one of our homes. There's an old lady across the street. Every time it snows, we just go over and automatically do her driveway."

Asked about staffing for the home, the director commented, "You really need live-in staff. Otherwise nobody really takes care of things."

Toward individualized community living arrangements. Throughout Wisconsin, counties and agencies are developing individualized community living arrangements as alternatives to group homes. These are called different things: supportive apartments, individualized service options (ISOs), or options in community living. Macomb-Oakland in Michigan refers to this approach as the "supported independence program," while Region V in Nebraska calls these alternatives "supervised apartments." In contrast to the traditional group home model, these alternatives fit the program to the individual and not vice versa. The concept is deceptively simple: find a home, whether a house, apartment, or other dwelling, and build in the staff supports necessary for the person to live successfully in the community. Inherent in the concept is flexibility. Some people, for example, those with mild disabilities who function relatively independently, may need only part-time support or merely someone to drop by to make sure they are doing okay. Others, such as people with severe disabilities and challenging needs, may require full-time staff support. Nothing in the concept precludes small groups of people from living together. However, when people are placed together, this should be because they choose to live together and happen to get along.

While many agencies in Wisconsin are exploring individualized community living arrangements, Options in

Community Living (not to be confused with the state's Community Options Program or COP), a private, nonprofit agency based in Dane county, has led the way in developing and refining this approach. Options may legitimately be said to be one of the most innovative and responsive agencies in the country. Indeed, one would be hard-pressed to come up with any other agency that does a better job of meeting the individual needs of people with developmental disabilities. Options recently developed an excellent resource manual that describes its approach in depth (Johnson, 1985). This is must reading for anyone interested in developing individualized community living arrangements.

Options supports approximately 100 people living in apartments and houses in the community. Initially, Options served people with mild mental disabilities. With special project funding including CIP, it has begun to serve people coming out of institutions who have more challenging needs, including people with physical disabilities.

All Options clients rent their own homes. For 17 people, Options employs live-in staff to provide full-time support, including personal care to some clients who have physical disabilities. Some Options clients hire their own staff, referred to as attendants. For these people, Options acts as a broker. It recruits, trains, and works with clients to learn to supervise their own attendants. Options staff maintain close contact with clients and attendants and

provide regular support and training to both. In some cases, Options uses foster care funding and licensing to arrange for "paid roommates" who provide companionship and support in clients's homes. Options provides oversight and monitoring to these situations as well.

While Options has developed a number of good ideas and practices for supporting people in the community, it would be misleading to suggest that what makes Options successful is its technical expertise. To the contrary, what seems to make Options so responsive to its clients are nontechnical matters. First of all, Options is committed to a core set of values. As reflected in agency policies, management practices, and the design of its services, Options places an equal emphasis on community integration, individual autonomy, and quality of life. It is not always easy to balance these values, but Options seems genuinely to try. Further, Options is a small, human-scale organization. Free of bureaucratic trappings, Options can maintain a strong sense of mission and personal responsibility among its staff. Indeed, the agency goes out of its way to involve all staff in decision-making and policy-setting. Despite pressures to take on more clients, Options has decided to limit further growth. It fears that expanding its services would come at the expense of quality.

Finally, Options is open to change. Part of this is built into the design of its services. As the director

explained, "Our models are flexible. If it is not working, change it." Options also invites external review of its services and, most important, seems to take seriously recommendations and suggestions for improvement.

HARVEY* AND SAM*

Harvey and Sam live in an apartment in Madison. Funded by CIP, Harvey moved to the community in late 1985 after spending most of his life at a state institution. He strikes one as a pleasant and gentle middle-aged person. He uses an electric wheelchair and a communication board. He communicates with simple one-word symbols. Sam is around 60 and seems bright and talkative. He has been living in the community for quite a few years after being released on "parole" from an institution some time ago. Harvey and Sam also live with Bob,* their paid attendant, who was recruited through Options and is officially employed by them.

Their apartment has three bedrooms, a living room, bath, dinette, and kitchen. It is furnished with older, though nice, furniture. The living room has a sofa, several chairs, and tables, and a lamp.

Harvey works five days a week as a clerical worker at the State Department of Health and Social Services. This is a volunteer job. The job was located through Community Work Services, which places people with

severe and moderate disabilities in typical jobs in the community.

Bob is a college student who is supporting himself through school. As a live-in attendant, he is paid $800 per month, $150 from adult foster care payments for Sam and $650 from CIP for Harvey. Harvey requires significantly more assistance than Sam.

Bob gets two weekdays and two weekends off a month. Two relief staff come and live at the apartment when he's off. One staff person provides support for 30 hours a week and is paid $4.50 an hour. Another person provides weekend coverage when Bob is off (paid $60 per weekend). Both positions are funded through CIP.

The lease for the apartment is in the names of the two men with disabilities living there. They split all apartment expenses three ways.

When asked what he likes least about the job, Bob answered, "Not getting any benefits." When asked what he liked best, he said, "I like Harvey and Sam. If I didn't, I wouldn't stay here."

Options staff provide case management and training in daily living skills to Harvey and Sam. Harvey, Sam, Bob, and an Options staff member hold weekly meetings. A physical therapist, occupational therapist, and nurse also come to the apartment to work with Harvey.

Bob mentioned that they all went out to dinner the

day before. He said that Harvey goes bowling on Saturdays and will begin swimming on Tuesdays. They all go shopping every two weeks. Later that evening, I came across Sam and Bob at a local restaurant/bar where they were stopping for a drink after going to the store.

When asked if they would be willing to have their picture taken, Sam went over to Harvey and put his arm around him. They seemed like friends as well as roommates.

Columbia county contracts with a small private agency to support people with mental and developmental disabilities living on their own. It hires support workers or "friendly visitors" recruited from the local neighborhood to provide support to people for up to 20 hours per week.

Describing the support workers, the county director stated, "They're ordinary people in the community, but extraordinary in many ways. We look for people with the following qualities. They have to be ordinary in the community. They have to be respected people, not people who have to earn respect. They have to be local folks. They know other people. The person has to be of the community. People have to be connected to the community. They get out and around and know things in the community."

The county director gave some examples of what the support workers do for people: "They get the person to

church if the person wants to go. They take the person grocery shopping. They get the person out for recreation in the community. They work on appropriate social and sexual responses, either individually or in groups. . . . You have to start out giving a lot of support to people. If you're setting up an apartment for the first time, you need someone to help you with where to put your knives, forks, and spoons."

He proceeded to explain how support workers are matched with people: "Step one is to identify the client. The case manager looks at his strengths and weaknesses. Step two is to find a support worker who has the characteristics we need and the time to do what has to be done. They've found a lot of people through the local paper--not the ('Pennysaver'), but the regular paper. Step three is to put them together. Step four is to start to define what kinds of support the person needs. Step five is to find out how much time the support worker can afford."

The agency hires one supervisor and supports about 25 people in the community at any given time. The county pays the agency about $15 an hour for services and this covers transportation, insurance, office expenses, and wages. The support workers, who are employed by the agency, earn around the minimum wage. In order to help prevent a cash flow problem for the agency, the county pays the agency up-front expenses for the first several months of the year.

Columbia county has also set aside funds to help people living on their own deal with the expenses of setting up a home. As the county director explained, "We set up a closet of materials for people. We went out and bought a lot of stuff on sale. They can use or rent things. We had a TV they could rent. We had dishes, brooms, dustpans, bicycles, colanders. When people start out, they have a lot of front-end expenses. You have to have some stuff available so they can live. You let them use some things or rent them. The support workers help them buy their own things over time. . . . We also had a pot of money to help people with things like security deposits. We'll put down a security deposit and then they pay us back over time."

Columbia county's approach to supporting people on their own is simple and straight-forward and sounds effective from both a cost and humanitarian vantage point. In many communities, these same people would either be in more restrictive group homes or left to fend for themselves on he streets.

The "person-centered" options springing up throughout Wisconsin are innovative and responsive to people's individual needs and desires. There is no doubt that this is the right direction in which to move.

The Community Integration Program

Wisconsin's Community Integration Program (CIP)

provides funding and support for innovative services for people with developmental disabilities coming out of institutions.

For good services to be put into place in Wisconsin, it usually takes three things. The first is a competent agency; the second is a committed county; and the third is a state program to support the services. The Community Integration Program (CIP) is just one of the state programs that has been used to fund innovative community services in Wisconsin.

Many of the innovative programs described in this report are funded through CIP. It is doubtful whether any of the people described in the individual profiles in this report would be living in the community today without this program. As stated by Harvey's attendant, Bob, in Options, "If it weren't for CIP, Harvey would still be in the institution."

When viewed in the narrowest possible terms, CIP is Wisconsin's Medicaid waiver program authorized by the federal Omnibus Reconciliation Act of 1981. Under the Medicaid waiver, states can request a waiver of federal regulations to provide home and community-based services to people who would otherwise be served in an Intermediate Care Facility (ICP) or Intermediate Care Facility for the Mentally Retarded (ICF/MR).

Wisconsin received federal approval for its Medicaid

waiver in October, 1983. Under Wisconsin's waiver, funding can be provided for three categories of services: (1) case management; (2) habilitation (a broad category that includes supportive home care, daily living skills training, day services, pre-vocational services, supported employment, home modifications, adult family home, foster home, and others); and (3) respite care services. The waiver program is predominantly for people leaving state institutions. However there is a small capacity to divert (prevent institutional admissions) for up to 50 people a year through new previsions in the CIP program. Built into Wisconsin's Medicaid waiver, and hence CIP, is an extensive needs assessment and individual planning process.

As of January, 1987, 40 of Wisconsin's 72 counties or 34 of the "51 Boards" participated in the CIP program. TABLE I provides a breakdown of the counties, along with the number of people funded through CIP, while FIGURE I illustrates county participation.

CIP funds are set at a standard rate. As of October, 1986, the CIP per diem is $80, which is supplemented with a Supplemental Security Income-E exceptional payment of $17.30, for a total of available funding of $97.30. This is the amount of funding available to counties as an average across all "CIP participants." In other words, counties could serve some people at a lower rate and some at a higher rate as long as they did not exceed this average amount.

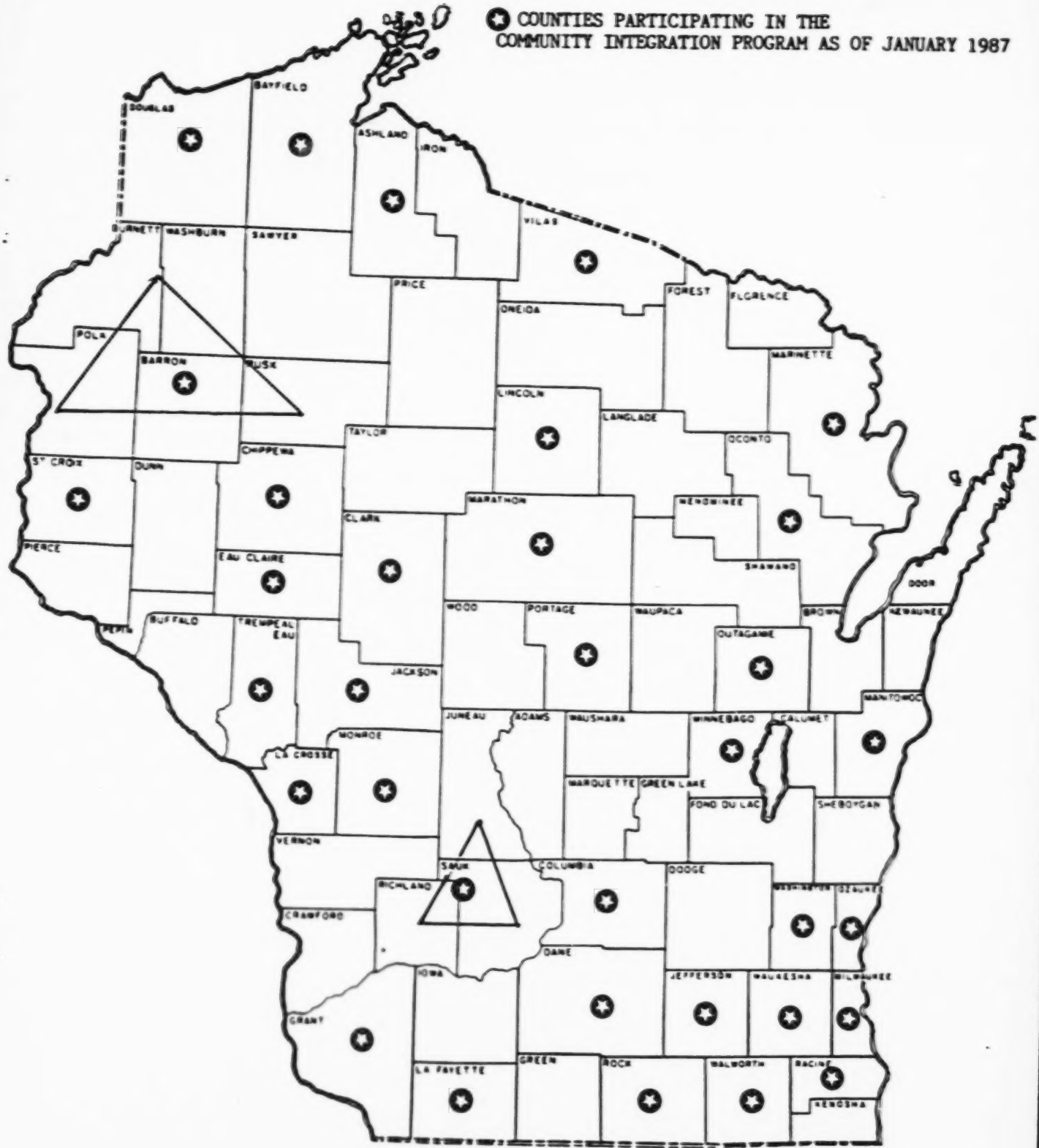
TABLE I

Community Integration Program

County Participants as of January 1, 1987

	DIVERTED/	STATE DD CENTER			TOTAL
EASTERN REGION	REPLACEMENT	CWC	NWC	SWC	9
Oconto			1		1
Marinette			3		3
Winnebago			1		1
Outagamie		1			1
Manitowoc		1		2	3
MILWAUKEE		3		17	20
NORTHERN REGION					14
Ashland			1	1	2
Bayfield			1	1	2
Douglas			1		1
Linclon			3		3
Marathon			2		2
Portage			2		2
Vilas			2		2
SOUTHEASTERN REGION					31
Racine		1		13	14
Washington	1	1		7	9
Waukesha	2	1		1	4
Ozaukee				2	2
Walworth	1			1	2
SOUTHERN REGION					35
Columbia		2		1	3
Dane		11	2	3	16
Grant				1	1
Lafayette	1				1
Rock		4	1	7	12
Tri-County (Sauk, Juneau, Richland)			1		1
Jefferson	1				1
WESTERN REGION					40
Chippewa			2		2
Clark			1		1
Eau Claire			8		8
Jackson			4		4
LaCrosse		2	5		7
Monroe		1	1		2
Northern Pines (Barron, Burnett, Polk, Rusk, Washburn)			9		9
St. Croix			4		4
Trempealeau			3		3
TOTAL PLACEMENTS					149

FIGURE I


COUNTIES PARTICIPATING IN THE
COMMUNITY INTEGRATION PROGRAM AS OF JANUARY 1987
DOUGLAS
BAYFIELD
ASHLAND
IRON
BURNETT
WASHBURN
SAWYER
VILAS
PRICE
FOREST
FLORENCE
ONEIDA
POLK
BARRON
RUSK
MARINETTE
LINCOLN
LANGLADE
TAYLOR
OCONTO
ST CROIX
DUNN
CHIPPEWA
MARATHON
MENOMINEE
CLARK
PIERCE
EAU CLAIRE
SHAWANO
DOOR
WOOD
PORTAGE
WAUPACA
BROWN
KEWAUNEE
PEPIN
BUFFALO
TREMPEALEAU
OUTAGAMIE
JACKSON
MANITOWOC
JUNEAU
ADAMS
WAUSHARA
WINNEBAGO
CALUMET
MONROE
LA CROSSE
MARQUETTE
GREEN LAKE
FOND DU LAC
SHEBOYGAN
VERNON
SAUK
COLUMBIA
DODGE
RICHLAND
WASHINGTON
OZAUKEE
CRAWFORD
DANE
IOWA
JEFFERSON
WAUKESHA
MILWAUKEE
GRANT
LA FAYETTE
GREEN
ROCK
WALWORTH
RACINE
KENOSHA

Counties can also supplement funding to CIP participants through COP and other sources.

The CIP per diem is significantly lower than that of state institutions. By maintaining a lower per diem for CIP, the state seems to cost itself and the federal government additional money.

When it was first planned, it was estimated that 110 people would be moved to the community through CIP each year. Actual placements have fallen far short of this projection. During CIP's first two years, 51 people were actually placed. As of January, 1987, about 149 people have been placed through CIP.

Since counties are responsible for community services, CIP, as a state program, serves as a carrot on a stick, nothing more and nothing less. In an interim evaluation of CIP conducted by the state's Division of Policy and Budget, county factors were identified as the major barriers to CIP placements. The reasons range from a lack of existing services within the counties to a lack of funds for start-up, administration, and planning and an inadequate per diem.

While CIP might be narrowly viewed as a funding mechanism, it is much more than that. Known for their deep commitment to the people they serve, CIP's staff are actively involved with people placed through the program and provide training, technical assistance, and support to both counties and agencies.

Counties participating in CIP express satisfaction with the program and see many advantages to their involvement with it. The interim evaluation of CIP bears this out. In addition, officials in Dane, LaCrosse, and Columbia counties point to many benefits through the CIP program.

According to Dane county administrators, CIP funding, while limited in some ways, is higher than that available through most state programs, and this makes it attractive to serve at least some people. They also pointed out that CIP funding made it possible to develop programs that benefitted people beyond CIP clients. A Columbia county administrator pointed out that a problem with CIP is that it doesn't pay for administrative costs, but if services and staff are in place, "CIP pays." He added, "It really helps to be able to average costs across clients." Both Dane county and LaCrosse county administrators and staff believe that CIP has helped them develop the expertise to serve people with severe disabilities. A Dane county administrator stated, "The CIP program forces our community to become more competent. The community won't become ready until you have people with high needs." A LaCrosse county case manager echoed this sentiment: "Because of the program, we have models now. We can serve people with high needs in the community." He added, "We also get a lot of technical expertise from CIP. (A CIP staff member) has been here a lot teaching us 'Gentle Teaching.' We can also get answers to questions about

Medicaid laws."

The LaCrosse county case manager noted that CIP helped county staff to deal with parents: "CIP gives us a reason to talk to families about community integration, an opportunity to educate them. Otherwise we probably wouldn't have much contact with them. . . .It helps to be able to tell parents that there is state support and knowledge available to us. It gives them security."

This same case manager said that CIP made county staff feel less isolated from things happening in other parts of the state: "CIP also helps us see the forest and the trees. We can get longitudinal feedback about how we're doing. CIP prevents you from being an enclave. You can get the message out about LaCrosse and we get ideas from other parts of the state. CIP comes and visits, too."

People in all three counties acknowledged that the CIP needs assessment and individual planning process is time consuming. However, they also felt that this process was essential to guarantee service quality. As a Dane county administrator commented, "It's a real job to put together a CIP plan, but it makes a difference. It really helps."

When asked why some counties might not want to participate in CIP, county staff gave different reasons. One administrator said that counties prefer "discretionary funds" rather than "earmarked monies." Another stated that some counties are skeptical of federally funded programs and want

guarantees that they will not be cut. A third said that counties that have not developed services for people within their own communities will have a difficult time serving people through CIP: "To use CIP you need an infrastructure of services. You have to have services you can build on."

Baring any major change in state and county responsibilities and mandates in Wisconsin, the success of CIP will be determined by the counties. It will depend on their willingness and ability, in the words of one county administrator, "to take care of our own." Another county administrator put it this way: "It's a good thing for clients. People don't need to be in institutions."

CONCLUSION

Over a dozen years ago, when the President's Committee on Mental Retardation issued its report praising Wisconsin's plans, community integration was an idea. Today, it is a reality at an increasing number of places across the country. Many of these can be found within Wisconsin.

In contrast to Michigan, Nebraska, Rhode Island, Pennsylvania, and other states, Wisconsin has not received national recognition for its community services in recent years. This is ironic, since many of the services in place in Wisconsin are as innovative and integrated, if not more so, than those in these other states.

Yet the national statistics do not present Wisconsin in

a positive light. In terms of its community placement efforts, it ranks below many states that have not done nearly as well in developing truly integrated services in the community. And fairly or unfairly, Wisconsin carries the reputation of a state in which "deinstitutionalization" has meant "reinstitutionalization"; that is, the transfer of people from large state institutions into somewhat smaller nursing homes and private facilities.

Wisconsin has some of the best community services in the country. It should build and expand upon these.

NOTES

1. Thanks to many people who cooperated with the site visit and took the time to discuss their views and provide valuable information: Paul Meyer, Julie Pratt, Sally Mather, Ann Booth, Bob Christianson, Keith Keller, Sue Hamilton, Dean Rupert, Michael Schroeder, Cindy Rowe, Marti Phillips, John Borquist, and Eileen Knecht. Thanks also to the many providers, families, and consumers who shared their experiences and opened their homes. Special thanks to Marilyn Wilson for coordinating the site visit and providing statewide information.

2. In addition, two Options apartments were visited in October, 1985. Gail Jacobs described Options during this visit. Information from this visit is incorporated into this report.

BIBLIOGRAPHY

Braddock, D., Hemp, R., Howes, R. Public Expenditures for Retardation and Developmental Disabilities in the United States: State Profiles. Chicago, IL: University of Illinois at Chicago, 1984.

Johnson, T. Belonging to the Community. Madison, WI: Options in Community Living, 1985.

Pratt, J. Community Residential Services for Adults with Severe Developmental Disabilities in Dane County. Madison, WI: Dane County Unified Services Board, 1985.

President's Committee on Mental Retardation. MR 72: Islands of Excellence. Washington, DC: U.S. Government Printing Office, 1973.

Taylor, S. J. From segregation to integration: Strategies for integrating severely handicapped students in normal school and community settings. The Journal of the Association for the Severely Handicapped. Vol. 7, No. 3, Fall, 1982.

Taylor, S. J., Racino, J., Knoll, J., and Lutfiyya, Z. The Nonrestrictive Environment: A Resource Manual on Community Integration for People with the Most Severe Disabilities. Syracuse, NY: Center on Human Policy, 1986.

Wisconsin Department of Health and Social Services. Community Integration Program: Guidelines and Procedures. Madison, WI: Author, 1983.

Wisconsin Department of Health and Social Services. Family Support Program: Guidelines and Procedures. Madison, WI: Author, 1985.

Wisconsin Department of Health and Social Services, Division of Policy and Budget. Interim Evaluation of the Community Integration Program.